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ABSTRACT

The booklet presents excerpts from a December 1984 conference (Washington, D.C.) on disabled and at-risk infants, toddlers, and their families. Parents' perspectives are offered on care for medically vulnerable infants and children (by the mother of a ventilator-assisted child), services for children with mild developmental delays (by a mother of a premature infant), and the effects on the family of a severely and/or multiply handicapped child. The keynote address explores the emotional needs of parents coping with the birth and life or death of a potentially disabled child and emphasizes the need for emotional support and information. A final paper describes negative assumptions held by professionals about parents' ability to objectively observe, set appropriate goals, and teach their children. (CL)

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Parents of Disabled and At-Risk Infants and Toddlers Speak to Professionals

1985

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National Center for Clinical Infant Programs

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The National Center for Clinical Infant Programs is a non-profit, tax-exempt corporation. It was established in 1977 by outstanding representatives from the fields of mental health, pediatrics, child development, and related fields, as well as community leaders, in order to improve and support professional initiatives in infant health, mental health and development.

Introduction

"If we're going to be successful with families, we're going to need to reorient as professionals. We're going to need to look to parents as leaders, parents as the experts, parents as the bosses. We're going to need to ask them to join us cooperatively as equals in this partnership so that we create a reality out there that matches what all of us want to see." Lisbeth Vincent

"The only way to discover what any collection of human beings needs is by listening to each one." Ann Oster

In December, 1984, a conference on "Comprehensive Approaches to Disabled and At-Risk Infants, Toddlers and Their Families" was held in Washington, D.C. Jointly sponsored by the Division of Maternal and Child Health in the U.S. Department of Health and Human Services, the Office of Special Education and Rehabilitative Services in the U.S. Department of Education, and the National Center for Clinical Infant Programs, a non-profit organization, the conference brought together practitioners, researchers, administrators, policymakers, planners and parents from a wide variety of disciplines and backgrounds. For many participants, the conference provided their first opportunity to learn about the work and concerns of early childhood professionals in fields and settings quite different from their own, and the first chance to hear parents of disabled and at-risk young children present their ideas and experiences.

Parents were "equals in the partnership" (a phrase used by Lisbeth Vincent in one of the opening addresses) which produced the "Comprehensive Approaches" conference. Yet they were more than equals in their individual and collective eloquence and impact on the nearly one thousand participants in the meeting. Even while the conference was still in progress, it was clear that the voices of parents need to reach a wider audience. This booklet is an attempt to make that happen.

Toward an Era of Family Partnership

KATHRYN BARNARD, Ph.D., R.N.

We need to begin to view our work with families as a partnership in which we are consultants, but the families are in charge.

Professionals are at a new stage in working with families. We are at the beginning of an era of family partnership.

For a number of years the attitudes of professionals working with families have seemed to say, "Tell us what your problem is and we'll fix it." In that "pathological" orientation, we have implied that if *you* have a problem, *we* can take care of it, that professionals are, in a sense, in control.

We professionals need to change our orientation in this partnership. We need reframe the question to ask simply, "How can we help you?" We need to begin to view our work with families as a partnership in which we are consultants, but the families are in charge. And it is on the care of their child that we are, in fact, consulting them.

There seem to be stages in achieving a family—professional partnership, stages which go something like this.

- First we begin to talk: "Yes, parents should be involved." We talk about parents' involvement and we talk about getting them on committees.
- The next stage comes when the service delivery agency says, "Parents are involved. They are working in our center; they are deciding some of our policies."
- The third stage is one I hear reflected in the phrase, "We use parents as part of our service delivery program."
- And what to me seems to be the goal that we're working toward is reflected in the statement, "Parents are the core of our team."

It is important to remember that the job we have to do in assisting parents with the care of their infant or toddler with a disability is quite different from the

These remarks by Kathryn Barnard, were delivered as part of the final synthesis of the "Comprehensive Approaches" conference.

job that we have to do when children are of pre-school age. What are some of the issues involved? Stabilization of the infant's physical well-being is very important. Helping parents to understand and to establish goals for the child is equally crucial. Until that is done, it's hard, many times, to move on and to be psychologically available either as parents or professionals—to really get involved in the work of early intervention.

I am calling for a major reordering of the emphasis in early intervention for children from birth to three. I would like to see professionals, in fact, become consultants to families who are taking care of their children. We will have reached the objective of *this* conference if in five years we hold a meeting called "Comprehensive Approaches to *Families* of Children Who Have Developmental Problems."

Comprehensive Care for Medically Vulnerable Infants and Toddlers: A Parent's Perspective

JULIANNE BECKETT

Mary Katherine Beckett was born March 9, 1978, at St. Luke's Methodist Hospital in Cedar Rapids, Iowa. Although premature and only weighing in at 2 pounds, 3 ounces, Katie had very few medical problems. She required only an oxygen hood for the first 48 hours and continued to grow at a rate which allowed her to come home May 6, 1978. She was a "normal" baby in every sense of the word. On September 1, 1978, she was back in St. Luke's Hospital, only this time in the Pediatric Unit for observation. Later, it would be determined she was suffering from viral encephalitis. On September 2nd, Katie aspirated and severe respiratory distress complicated an already serious illness. This is where our story begins.

It was a beautiful Sunday morning; a day I thought could never by replaced by another. But that is a story of sadness. That sadness turned to joy three years later, December 19, 1981. That's the day we began our new story; a story of hope, of happiness, of beginnings.

The problems we have faced have been difficult ones, but Katie has been labeled somewhat of a "miracle child" because she has made significant progress in overcoming the horrifying after-effects of viral encephalitis. That glimmer of hope has taken us through each incident seemingly making our bond stronger.

When Katie's doctors told us we could take her home, it seemed as if our prayers were answered. All the learning processes seemed minute compared to the joy of having us together. It was at this time that we were notified that our Medicaid coverage would not extend to home care costs.

We had always carried insurance to protect ourselves, but with the soaring medical costs, it is impossible to foresee a catastrophic illness using all of your private insurance. Having exhausted all lifetime

Major Medical coverage on BlueCross/Blue Shield, a child with a wonderful potential for a full life at the age of three years was left with no health insurance coverage and no governmental insurance should we take her home, where she belonged.

The next few months were exhausting—fighting governmental red tape, reviewing the brushes with death that had occurred over the last few years, and facing rejection after rejection.

Having exhausted all lifetime Major Medical coverage on Blue Cross/ Blue Shield, a child with a wonderful potential for a full life at the age of three years was left with no health insurance coverage and no governmental insurance should we take her home, where she belonged.

Private funding was another road taken, but each organization examined explained that we did not fit into their guidelines, since they were established mainly for educational and informational purposes.

We even attempted to apply for grants, but were rejected because Katie was an individual and the grants were designed for group aid. Their purpose was mainly for research in an area which would benefit a greater number of the general populace. There was no broad base for support; therefore, we were non-essential to their program.

If we *only knew then* what we know now!

In June, 1981, we turned to our congressman, Tom Tauke. Here, we met a willing response to our plea for help. It was judged it would be difficult to get Congress to schedule a private bill to alter the present regulations. It would be two or three years before it would even come up for debate, so we were given support to apply for an Exception of Policy. These efforts and analysis of the problem took months, with much correspondence with state agencies. It was very agonizing, and by the end of the summer, our frustrations were high.

It was at this time that Congressman Tauke sent our case to then Secretary of Health and Human Services, Richard Schweiker. On November 4, 1981, Congressman Tauke received a letter *rejecting* our Exception to Policy due to what President Reagan later termed "hidebound regulations". It was then that Congressman Tauke turned to Vice President Bush.

Through the President's, Vice President's, and Secretary Schweiker's intervention, our daughter, Katie, was able to come home. But hundreds of other children do not have this advantage. Hopefully, because of

our experiences, people can realize it *can* be done and life *can* be enriched for those children who have suffered so much.

You here today are the persons to help their plea be heard. *You* play an important role in the day-to-day *living and loving* of those children. We look to you for support and determination in commitment to home health care for everyone. For that commitment, a simple "thank you" does not seem nearly enough.

We need to convince our society that technology dependent children can *and* should *do very normal growing. They should be allowed the opportunities that we afford any human being.*

Katie Beckett has led a very unusual life, but no one will ever say they saw no purpose in her living. She has been set as a model for home health care. Her success in overcoming the serious after-effects of encephalitis have made her truly a miracle child. No one could foresee how well Katie could do at home. It had to be lived day after day, not without worry and strain.

Before leaving the hospital in December, 1981, all efforts were geared by state and private professionals to help Katie improve at home. They have truly been successful. Healthwise, Katie has improved remarkably. Serious illnesses are becoming less and less frequent since our initial discharge. We have been able to wean her off the respirator for nap times, and her rate has dropped several settings from the initial ten.

Katie was able to attend preschool in her first year home, and it was the consensus of many of the parents that Katie had grown the most of any of the other children. Her need for socializing skills was very evident in the beginning of the school year, but by spring, she was just one of the kids. It was a time when we saw peer pressure work in a very *positive* way.

Last year Katie was mainstreamed in kindergarten with students in a private school. She developed at a rate far beyond anyone's previous expectations. Reading, writing, and even a little arithmetic, the child with a trach was outstanding and even made the move to the higher level of students because her learning ability is so far advanced.

Much of that ability can be credited to her speech therapy. Katie must still have speech therapy three times a week, but for a child who has worked with a speech pathologist since the age of one year, learning

has become a fun experience. It was believed before her discharge Katie would have to sign to be communicative. This is no longer the case. The growth in the last two years and her exposure to other children in a learning situation have improved Katie's speaking to a level where she no longer needs to sign and is not even asked to repeat to be understood. Her vocabulary ability alone was tested out average 7 years, and her level of understanding that of a 6 year old. This testing was done shortly after Katie's 5th birthday. She will need to continue speech therapy for more tongue control for several years, but there is now a light at the end of the tunnel.

The only educational drawback Katie seems to have is in the fine motor skills, but after working with a private tutor from the Grant Wood Area Education Agency since her discharge, she is able to get a tighter control and guide her hands through writing, cutting, and other fine motor skills.

All of these success stories occurred because we work together as a team. Speech therapists, physical therapists, respiratory therapists, public health nurses, teachers, school officials, psychologists, sociologists, and suppliers are committed to one thing—helping this child grow.

Mark and I are not trained medical professionals, but the years we spent watching Katie grow and the support we received from nurses, doctors, and therapists while she was in the hospital reinforced our belief that we could care for her at home. We knew also that once out of the hospital setting, we had a network of community-based support which once and for all showed how much people care, and how much of a role we all need for them to play in our lives. You are those supporters; those people who care.

Can other children progress so at home and can parents learn to care for their children in the home environment? I would say *very definitely* YES! We need to convince our society, however, that technology dependent children *can* and *should* do very normal growing. They should be allowed the opportunities that we afford any human being. We must be aware, however, that not every parent is able to cope physi-

cally, mentally, or emotionally with having a chronically ill child in the home. However, I do agree that with the right training and with a greater public awareness, the fears can be negated. We must also be aware that every child's case is different. I believe we need a strong case management program and assessment as follow-up to the release of children into their parents' care. This helps to carry the burden and takes a supportive effort by trained professionals. It provides a psychological boost to parents, especially in the first few months of home health care.

You, as professionals, carry the on-going burden of continual support. You share in the family's successes as well as failures. You are a part of the problem-solving team; one who *must* be aware of the emotional bonds which pull the family together in time of crisis. Your role is essential and paramount to all others, with the exception of the parental role. You are forging a new frontier in home health care.

This role, which was thrust upon Mark and myself, resulted from the growth of modern technology. However, preparation for this "new generation" of children dependent on technology for survival is still being expanded. We are lucky to have such wide, community-based support to develop a program essentially for Katie's needs. Therefore, we know programs can be developed throughout the country, pulling all resources currently intact together to meet the needs of these children.

SKIP, our organization, acts as a parent resource group to support programs for home health care for the technology dependent. Our goal is three-fold. First, we educate parents, health care professionals, public and private funders, community-based agencies, and the general public on the advantages of and the need for home health care for these children. Second, we act as a resource for families and providers to assist in expanding programs and developing new resources to meet the needs of this "new generation". Lastly, our goal is to identify and access resource services necessary for family support. We feel this will lessen the handicaps imposed upon this nation's children dependent on technology, and will promote child and family self-sufficiency and auto-

nomy in the least restrictive environment possible.

Sick Kids (need) Involved People is this organization with such lofty goals. These goals, which may seem extremely hard to achieve, can be reached through cooperation and support. SKIP is unique, because it is run by parents who have overcome the problems. They are the parents who have children living at home on medical technology. They have made their home the "intensive care unit" and afforded their children the same opportunities of family, home, and love which cannot be realized in an institution.

Sick Kids (need) Involved People is run by parents who have children living at home on medical technology. They have made their home the "intensive care unit" and afford their children the same opportunities of family, home, and love which cannot be realized in an institution.

Katie did not lead a deprived life in the hospital. She was happy, loved, and stimulated; but the reality of home and family have changed and enriched her life so much more. Through SKIP, more children can live the reality of home care.

How do we do this? How do we know what family's needs are?

First, ask—some parents will be able to tell you what they need very soon after the initial crisis has occurred. Others it will take awhile—be there for them—be supportive—whatever their decision is. Continually reinforce, "together we can do what needs to be done for your child."

Recognize that the parent is an integral part of the care team. As soon as it is feasible, get the child back into the mother's arms. Help the bonding take place. Often times because they have relied on the professional to "make their child better", they feel they no longer can add anything to the child's life. Help them to realize that isn't so, that they make the "educated" decisions—that the child is their child—this will only help to strengthen them through the years to come. If they feel supported from the onset, they can become strong, loving parents.

Be honest, but be supportive.

How do we meet the needs when they leave the hospital? How do we make transition easier?

First make sure that the child's care plan is written with the community and home in mind. Answer what the medical needs of this child are through community agencies, and meet with hands-on care providers. Ask the family how workable this plan will

be—what they feel is necessary to meet the reality of home life. Remember, that child is their responsibility—they need to be involved in the decision making.

When the medical plan needs have been met and the community care plan has been written, and players have been identified, then concentrate on the family's other needs:

I know that parents and professionals can work together as equal partners in developing plans for care of the medically vulnerable. I knew I was supported, and listened to, and sought out to make decisions, therefore I can do that the rest of my life.

1. Secure funding to make sure that the child is coming home to a family whose biggest fear is not giving up every worldly possession to pay for home care. home care.

2. Plan for some type of relief for the parents. They will never forget totally their responsibility for that child they brought home, but give them an opportunity to get away for awhile to be who they are. With a medically vulnerable child your life revolves around their care. I wear my watch on Iowa time so I know where Katie is every minute. As long as the players I have put together for her do their job, she'll be fine. But I still need the time to get away to be Julie Beckett, not just Katie Beckett's mother, even though that role has given me the greatest pleasure in my life.

I know that parents and professionals can work together as equal partners in developing plans for care of the medically vulnerable. I've had the opportunity to do that, but it all goes back to our first few months after Katie's initial crisis. I knew I was supported, and listened to, and sought out to make decisions, therefore I can do that the rest of my life.

Our children have made us real. We have watched them cry in pain, suffer through testing, and still they can brighten our lives with the gentlest smile, the whimsical laugh. They have shown so many people what life truly is—not in the quantity of years, but in the quality of how life must be lived.

These children delight in the things this country holds so dear—home, family, and love. The home provides the security and stability that is not possible in an institution. The family provides the never-ending caring, the blessing of peace, and without a doubt the only kind of unselfish, understanding love needed so desperately in all of our lives.

These children are showing the way, finally being

recognized—not as those to pity, but those to envy. They have served their purpose in life through their giving. They show those whose lives they've touched that acceptance is needed only by those who cannot truly care about others. Those who care accept without condition.

Mild Developmental Delays From a Parent's Perspective

PAGE TALBOTT GOULD, Ph.D.
LENETTE S. MOSES

Some children born at risk for serious handicaps later turn out to avoid these worst problems and instead manifest only mild developmental delays. Despite this favorable outcome, however, these children can be an ongoing source of worry to their parents.

Imagine, for example, a child born twelve weeks prematurely weighing only three pounds who, among other problems, suffered respiratory distress, intracranial hemmorhages, meningitis, hospitalized from birth through his eleventh week of life. (It never ceases to amaze me how one can take eleven weeks of stress and worry and life and death situations and condense it all into one short sentence!)

The parents of this child are told throughout the child's early days that should the child survive, there will be the possibility of ongoing physical and neurological problems. The spectre of brain damage is raised at the outset and reinforced at the time of further head bleeds. When the pre-term baby begins to improve and it becomes clear that he will at one point leave the hospital, the parents rejoice at his strength and will to live, while wondering what the future will bring.

This child will be followed after homecoming by a team of specialists who will examine him regularly. The doctors and therapists who follow these tiny babies look for benchmarks and try to identify obvious conditions, but generally present an attitude of wait and see to the parents, who are anxious for definite answers.

These parents don't dare question the medical staff too much for pressure leads to resistence, and parents need the professionals as their allies and sources of comfort. So on that special day when the still-tiny infant goes home, the parents accept the future, grateful they have a baby to bring home at all.

All parents worry about illness and accidents, but

parents of formerly hospitalized babies are particularly afraid. Since many babies have been kept on monitors until the day of departure from the hospital, parents are terrified to leave their babies unwatched. A funny cough, a strange gurgle, an unusual color all leave the parents weak with fright, uncertain of the proper action to take.

Sooner or later that baby, so vulnerable at birth, loses his fragile appearance and begins to look and act more like a normal child. The parents, however, retain their vulnerability and continue to look at their baby with crisis-colored glasses.

It can take months before the parents can sleep soundly at night or comfortably leave the baby with another caretaker. Sooner or later the baby, so vulnerable at birth, loses his fragile appearance and begins to look and act more like a normal child. The parents, however, retain their vulnerability and continue to look at their baby with crisis-colored glasses.

Most premies can be expected to experience delays in development. But since the barriers of viability have bee pushed back to greater and greater extremes, studies must be constantly updated regarding what to expect in terms of their development. Rarely do premies under three pounds catch up with their peers within one year. Physical milestones are considerably delayed, but so too are developments in the areas of speech and cognitive skills.

Parents and family members of these children are relieved when a baby finally walks at twenty months, only to worry again when the baby is saying only a few words at age two. It seems that one milestone met precedes another one to surmount. Doctors' assurances aside, few parents of formerly vulnerable infants can put aside early fears and face each hurdle with equanimity. For who's to say that the newest hurdle won't present evidence of a heretofore unidentified problem?

Growing up begins to seem like a minefield. Wherever one steps there is the potential for disaster. In other words, the parents are always on their guard, looking for a problem. "That's no way to enjoy your child's childhood," you might say. But we parents are set up for this scenario. We almost wish that someone would say, "Aha! You've been right all along. Your child does have a definite problem, and this is what it is . . ."

Instead we live with the term "developmentally delayed" and wait and wait until the child walks, talks,

swims, goes to school, reads, always wondering if a problem in specific area is perhaps a manifestation of a specific diagnosible condition.

As these children reach school age and become less and less noticeably different from their peers, the parents wonder what their child would have been like if born on time—would he still have had trouble concentrating and sitting still, have been more interested in academics, been more competitive, have been bigger and stronger?

Parents can share feelings and experiences with another parent who has been there, one who can empathize (not merely sympathize), and one who can validate what is being said. In some cases, these support parents, who had been total strangers and may have very little else in common with the new parents, may be even more important for a time than the extended family or friends.

Questions and concerns are often intensified as other children are added to the family, siblings who develop at so-called normal rates. Their skills seem precocious to the parents, who waited many months longer for the first child to achieve the same milestones. It may be difficult to balance attention shown to each of these siblings, as well. Time spent in therapy, for example, is not always viewed as "fun," quality time to the child experiencing it. But the sibling still sees it as time the parent spends with his brother or sister. How does a parent decide what is "fair?"

The parent is involved in his community, too, and may have as much trouble finding a true peer—a parent with a special child—as his child does. It is very difficult for a mother to watch neighbors' children growing according to the books while her child does not. This is where parent support is so vitally important. Parents can share feelings and experiences with another parent who has been there, one who can empathize (not merely sympathize,) and one who can validate what is being said. In some cases, these support parents, who had been total strangers and may have very little else in common with the new parents, may be even more important for a time than the extended family or friends. Sometimes grandparents and neighbors have a hard time handling the situation themselves, and may not be able to offer support to the parents.

Eventually, the memories of the horrors of early days give way to a feeling of pride that the child survived and the family became whole again. But it's important for those involved with the care of these families to understand that concern and anxiety does not dissipate when the possibility of a severe disability has

been ruled out, particularly if the potential for brain damage was originally raised by the medical staff. Professionals should assume the responsibility of helping the family deal with their ongoing concerns no matter how long they might last or how real they might be.

Perhaps one of the most important goals that all parents of developmentally delayed children should strive for is to help build their child's self-esteem. From the earliest days onward, a child who feels good about himself will be happy and at peace, and will have the confidence to take on the challenges his life may bring. This is especially important to develop before other children start telling him he is different.

Another wonderful consequence of this self-assured little one is that the child's parents will take on an air of confidence themselves. They can feel successful in their parenting skills. Even if they have not been able to cure a condition or speed their child's development, or even determine a specific problem, they have raised a well-adjusted little human being. What an achievement!

The professional's role in this is to guide a parent in seeing the child's strengths, as well as his weaknesses. How often parents and professionals alike concentrate on a child's problems and overlook the special traits and abilities that make him such a unique little person. A few complimentary words on a mother or father's positive approach will go a very long way, as well.

How fortunate are we parents whose tiny babies have survived and are thriving. Be assured that we are not trying to create problems. Instead, we want to give our special children all we possibly can, including the best treatment for a specific condition. When such a problem cannot be pinpointed, we continue to serve as vigilantes in case something has been overlooked. We need reassurance and understanding to help us accept our children as they are and to learn to bask in the glory of each of their achievements and their special offerings to life.

Severely and/or Multiply Disabled Children

FERN KUPFER

I'm Zach's mom. Zachariah is eight years old; he lives in a children's convalescent home (which has always unnerved me as a euphemism). Convalescent means to get better and none of the children there are getting any better.

What is Zach like? If I were to describe him to you I would say: he doesn't do anything. He doesn't sit up, he is in a very adaptive wheelchair; he has never spoken. He has a good sense of humor, which seems strange. He responds well to songs and he laughs at the funny parts of "Old MacDonald". He's a "boy boy", which also seems strange for how very severely handicapped he is. He likes rough "boy games." He likes rolling on a mat with my husband when he holds him. He likes being talked tough to, so that we sometimes take his pajama top and rough him up, and nurses sometimes look at us strangely. And that seems strange to me because he has a personality, as very severely handicapped as he is. I don't want to seem like I'm happy about who he is and that I accept who he is. I think there is a part of every parent of a handicapped child who is in chronic sorrow.

I see him about once a week in a place which is near where I work, and I enjoy seeing him. I like holding him. He's still like a baby to me, so it's real hard for me to see him getting bigger and bigger. And then I usually cry one exit off the expressway, and then in two more exits I'm at work and I'm perfectly fine and I teach a course and sometimes I tell jokes.

So it's a strange life, because I don't consider myself an unhappy person, and I'm doing okay, but there's a part of every parent who has a child who is damaged which is in perpetual mourning.

Zach lived home with us for two and a half years. It was a terrible time. I didn't want to get up in the morning. One of the speakers at this conference talked about "falling in love" with a baby and that struck

a chord in me, because I have a normal daughter who is now 12. When she was a baby I remember holding her in my arms and thinking "I love this child so much, I could kill someone who is going to hurt this child." When I was little I never understood my mother giving us the best cuts of meat, or the maraschino cherry from atop her sundae. I could never understand loving someone so much that you would give up those kinds of things. And when I had my daughter I understood that kind of love. It struck me when Zach was home and living with us, when he was a newborn, that I did not have those feelings for him. I remember thinking when he was sleeping that maybe he wouldn't wake up from a nap, that it would be crib death, and I would be released. And so I felt so dreadful with a part of me wanting my baby to die when I had this very intense love for my daughter.

I think there is a part of every parent of a handicapped child who is in chronic sorrow.

It took us a long time to figure out what was wrong with Zach. I don't mean to be smug, but I knew first and I knew right away. When Zach was a very young baby he did not connect with me in that way, he did not give back. He didn't look at me the way my daughter did. And so I didn't love him in that way. When he was three months old I took him to the pediatrician and I said "This baby cries all the time, I don't know what to do with him." I was doing those kind of custodial things: I was dressing him, I was giving him a bath. I had to make the effort to talk to him because there was not that reciprocity. And I said "There's something wrong with him." Zach looked great: he was chubby and blond and beautiful, and my pediatrician looked at me like: "This is a neurotic mother, this is an educated woman who's high-striv-ing; she wants this kid reading already." And he said, "No, he's perfectly fine." And I didn't say, "Put that in writing."

When Zachariah was about five months old I remember saying to a friend, "Do you think he could be retarded?" It was the first time I ever said the word out loud, and it choked me. And I remember she said to me, "No, he doesn't look any more retarded than you do." And he didn't! When I looked at him sleeping, looked at him awake, although he didn't do any-

thing physically when he looked at me, he was *there*. When he was about six months old and he still was not holding up his head, that began our round for the next two years of home interventionists, therapists, educational specialists, psychologists, social workers and doctors. I never had so many people come to me home—except for the doctors, who of course don't make house calls. And I can remember feeling that I didn't like it, that this was a real intrusion on my life and who I was as a mother, and I can remember feeling sometimes when the social workers came to call and the home interventionists came to call that I didn't want the house to be all picked up and us looking nice and us looking okay because I didn't feel okay. I felt like I was falling apart. And so there was a part of me that wanted to open the door in a ripped nightgown with a beer can in my hand to show that I really needed help. I need a great deal of help.

Zach lived home with us for two and a half years. It was a terrible time. I didn't want to get up in the morning. I remember thinking when Zach was sleeping that maybe he wouldn't wake up from a nap, that it would be crib death, and I would be released.

Zach cried *all* the time for two and a half years, unless he was held and rocked. It was not sufficient somehow to be seated and holding him; he had to be on the move. So consequently I held him and rocked him. My husband and I had great roaring fights about this because my husband said we were spoiling this baby. I said I didn't care, I could not stand to hear him wailing constantly. Sometimes we put Zach in his room, we turned up music, and he still continued to cry. I cannot tell you—well I just did—about what the tension was like in our house. I rode around in the car with him a great deal because that seemed to soothe him and so I got in the car with no place to go. He liked being strolled in the stroller, so I walked up and down the one mall that we have in Ames, Iowa—I don't know how many miles I put in up and down that mall. It was a very difficult time.

Later we discovered Valium for Zach. Well, actually, I took some of his Valium too, sometimes. Then we all had a good day. I always thought that there was something wrong with his connections, that he was in pain, that this was not his personality to be so complaining. Something hurt him, something was happening in his head that made him hypotonic, spastic, that made those muscle changes. And actu-

ally with the Valium he was relaxed. He is a very happy child now.

When he was two I did not see how I could endure taking care of a baby that just grew bigger and bigger and didn't do anything.

What happens to a family when you have a handicapped child? I think that really it is a myth that tragedy brings families together. It does not. We grieve very, very privately and men and women grieve differently. My husband is the "traditional man" and he grieved "like a man", which is to say that he did not cry, but his anger came out at inappropriate times, at dishes in the sink or a daughter not coming home on time, or something small and, I thought, silly. I cried all the time, I depressed my husband, I talked about Zach to every single person I knew, I asked all sorts of questions, I was on the phone all the time. When someone saw me on the street and said "How are you?" I took them seriously and told them. My husband went to work and there were people who did not know what went on in our house. It seemed as if we were separate families. As a consequence, when my parents called and wanted information about Zach—what tests was he having, how was he doing—they always wanted to speak to my husband because Joe said "He's doing okay, he's in this therapy program, we're really working hard with him" and he was very "up".

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I thought I was the more realistic one, he thought that I was very negative and sour. I thought that he was not being realistic and facing his feelings. I can't tell you how many times he said to me "Will you please stop telling me what I'm feeling?" So there was a great deal of tension in our house.

Having a handicapped child changes relationships among siblings. I think the most difficult thing is that there's so much focus on the handicapped child that we don't allow the siblings to act normal. Every person should be able to say at some time in his or her life, "I hate my brother; I can't stand my sister." You cannot say that when you have a cute, sweet, handicapped brother who doesn't do anything and whom everyone feels sorry for. The sibling cannot vent those ugly feelings. I remember one time Zach was

home for a visit—this was after he was placed—and he had just gotten a new wheelchair which was very spiffy-looking, and kids came from around the block because they wanted to walk him in his new wheelchair. My daughter must have been six or seven then and she came in the house really angry, and she said "No one wants to play with *me*, they just came over to see Zach." And something went off in me—I was in a rage. I thought, "You can walk! You can talk! You're a healthy child!" But I didn't say that because I read the right child psychology books, and I said "Sounds to me as if you're very angry." And she said "Yes, I am!" And I said "It's hard having a cute handicapped brother in a new wheelchair." And she said "Yes, it is." And that's all she wanted. She wanted to be able to be legitimately pissed off and jealous. And I think that families get "abnormalized" by the abnormal child because these ugly feelings are not brought to the fore.

Every person should be able to say at some time in his or her life, "I hate my brother; I can't stand my sister."

You cannot say that when you have a cute, sweet, handicapped brother who doesn't do anything and whom everyone feels sorry for.

Having a handicapped child changed relationships with my brother, who had a little boy the exact same age as Zach. I said to Ray (I say it frequently), "I can't be the kind of aunt to Abram that I should be. I can't go all out and love him that way because when I see him I see constantly what Zach could have been." I get mad at my brother when he doesn't talk enough about Zach. He doesn't ask about him: it's like he's an invisible child, like he's not there. I always want people to ask me how Zach is. One time after a visit my neighbor said "How was the visit with Zach?" and it was very bad, he was very sick at this time, the feedings came very slowly. And she just asked me and I burst into tears, and she said "I never know if I should ask you about him because then you cry," and I said "That's okay. Always ask me. I want you to know. I hate when he's 'not there'." We went on a family vacation and there were too many people who didn't ask me about Zach: I felt like he was never born, I felt like he was invisible. And I want to be able to cry to them. Then I get better, and then I'm okay. There's nothing wrong with that kind of feeling and crying.

There is a certain animosity that is just *there* between parents and professionals that will *always* be there

because you have these intervention programs, you can do this diagnosis, but you can't make our kids better. And when push comes to shove, that's really what we want. I don't care if he's identified with a label, a good diagnosis at age one; I don't care if 400 people came to my house with terrific programs and worked with him day and night to make him as good as he can be. The bottom line is, he can't be fixed. And that always makes a parent sad. And as a professional that's something you have to understand.

There is a certain animosity that is just there *between parents and professionals that will* always *be there because you have these intervention programs, you can do this diagnosis, but you can't make our kids better. And when push comes to shove, that's really what we want.*

Another reason for the animosity is that parents are an "in-group". Whenever I hear men talking about what women really want, I feel a certain "Huh! What do they know?" I would imagine that black people feel that when they hear white people talking about what blacks are like, that same kind of thing. Or handicapped people hearing able-bodied people talking about what the handicapped need. We're in this in-group, and we know. And it's an oppressed minority. Sometimes professionals who don't have a handicapped child are apologetic to me. I give a speech somewhere and I meet a professional and I say "Do you have a handicapped child?" she answers "Oh no, I'm sorry." I say "That's okay—you really wouldn't want one!" But as a professional you should keep in a part of you the idea, "I don't know what it's like. I have not been in this parent's shoes." And make yourself then a little less judgmental. But there is this anger that we parents have because we're in the know, but you're writing out the IEPs, and you're making the judgments and you're the one who's determining things.

I would like to read you just a brief section of my book.* It tells about relationships with doctors, but you could substitute any kind of professional because there *is* this animosity. I'm sure as professionals you have felt personally threatened, or asked yourself "What are they so angry about?"

"I both dread and anticipate going back to the doctors. Maybe now there is something they can tell us. [I think Zach was about 18 months at this point.] I resolve to be firm but pleasant. That my own heart is

Before and After Zachariah (New York: Delacorte, 1982).

breaking is of no consequence to medical diagnosis. Always with me is the knowledge that I am not behaving very well. Furious with the doctors, who are only guilty, after all, of having lousy bedside manners. Last year on one visit to Iowa City I remember a young resident, the second in what was a long series that day. As he came into the examination room, red-nosed, runny-eyed, crumpled tissue in his hand, he had a bad cold. Without a word of acknowledgement or introduction he sat down at the table and began interestedly flipping through pages of Zach's thick file, pausing to sneeze and blow his nose, searching through his white lab coat for another tissue. "Who are you?" I demanded, my voice filling up the little room. "Oh, I'm sorry." More nose blowing. "I'm Dr. Bruner. I'm looking at "——head scratching, searching the paper in from of him—— "Zachary's case." "That's Zachariah," I said archly. Why? Because the man did not introduce himself? Because he mispronounced a difficult name from the file? Why because the man had a cold did I wish to draw my nails across his smooth cheek, to draw blood?

Another time I was with a foreign doctor, a small dark man who spat out words in clipped English. He approached me in the waiting room. Standing very straight at attention, he pointed to Zach with a long index finger. 'He is your son?' 'No, a_____, he is my husband.' "

Actually, I did not say that, I thought that. That was parenthetical. I was outrageous, but not quite that outrageous.

When parents are together we do make jokes about professionals and doctors, but we do this not out of a personal vendetta. There is a free-floating anger that has to do, very simply, with our children not being whole, and there's really nothing that you can do about that, about fixing them. So sometimes when parents are aggressive and upsetting, I don't think you should take it personally.

One last thing. People who are in this profession of working with the handicapped have chosen it, and it is a profession that gives you a lot of self-esteem and a lot of good feelings. Everybody likes people and

admires people who work with handicapped children. It's almost a cliche when Miss America is being interviewed. They say "What do you want to do?" "I want to work with handicapped children." It's such an ennobling profession. Sometimes I speak at colleges and I see these very young, sweet girls who are going to work with the handicapped. And I look at them and I think "Oh, you are so young, and you really just don't know." But this is something that if they get into and they pursue, they have chosen and it makes them feel good. *The parents have not chosen this.* No parent would choose to have a child that is anything less than normal and whole. And so while we both want the best for our child, the best program, we also have to realize that we're coming from different places. You're coming from a place that gives you a lot of self-esteem. A parent of a handicapped child does not have that self-esteem.

Keynote Address

ANN OSTER

Two months ago, in Salt Lake City, Utah, Parents of Premature and High Risk Infants International, Inc. sponsored its first annual conference on Parent Care. This fledgling parent organization, running on the adrenalin and personal conviction of its members, had mustered the courage to invite Drs. Brazelton, Graven, Gorski, Mangurten and many other distinguished physicians, nurses and social workers to join parents in presenting research, clinical programs, and personal observations to an audience that we hoped would number 150.

There were a lot a surprises during the three days of the conference. When registration closed, nearly 370—professionals as well as parents—had come from as far away as Florida, Maine and Hawaii. There was an exhilarating sense of something big happening: the grass roots sprouting a new turf where parents and professionals who care about premature and at-risk babies could talk with each other and learn from each other. Mutual respect and trust grew before our eyes as a hospital administrator advocated hospital funding for parent group coordinators because he felt that peer support was cost effective. Developmental pediatricians discussed the need to make the bizarre, hi-tech environment of the NICU responsive to the human needs of babies, parents and staff.

It was an exciting notion that the technology centered approach to Neonatal Intensive Care is beginning to give way to technology supported care that focuses on human beings—not just because of altruism, but because hard evidence indicates that a humanized environment, and better informed, more empowered parents make a difference in the medical and developmental outcome of these babies.

Nearly as exciting was the clear implication that if parents and professionals could work together to

generate this conference, there was no limit to what they could accomplish together for families.

Today I have a similar sense of something big happening as we move closer to seeing disabled and at-risk babies in the real life context of their families and their communities. That at a conference of this stature parents are included as experts on family relationships is an enormous step toward a partnership with limitless potential.

I have a sense of something big happening as we move closer to seeing disabled and at risk babies in the real life context of their families and their communities.

I am going to talk today about the emotional needs of parents coping with the crisis of the birth and life or death of a potentially disabled child. And I want to examine how we—parents and professionals—can best respond to those needs. My own experience gives me both the advantage of a parent's view point, and the myopia of my own particular needs and circumstances. But my years of talking and listening to other mothers and fathers have taught me that although we may be able to generalize to the extent of predicting the likelihood of parental anger or fear or denial, the specific manifestations of those emotions are as varied as the individuals who feel them. The only way to discover what any collection of human beings needs is by listening to each one.

Five and a half years ago, when my son Nicholas was born prematurely, I felt more hostage than partner to a gang of powerful professionals who sustained his life and taught me the rules of a strange new variety of motherhood. I didn't question their competence in treating any of us: my husband and I needed to believe that someone had wisdom in this situation that had spun our lives out of control and made us wonder who we were and whether we were any good. The individuals stand out who helped me begin rebuilding a sense that I was worth something: the nurse who sat and talked with me when she had time, and loaned me a nursing text when I was frustrated by my ignorance; the child life teacher who asked how I was doing and then sat down to listen as I told her; the physical therapist who celebrated Nick for what he *could* do instead of defining him by his disabilities.

But so many of our contacts with professionals were frustrating or destructive to our self-esteem. We

were given very little information, and our skills training consisted more of prohibitions than positive action. So we became expert at handwashing and technical jargon about blood gasses and electrolytes. Instead of being instructed about how to deal with Nick's developmental immaturity, we were encouraged to play the strange nursery game of pretending he was a normal baby. One day I asked a nurse how this experience affected mothers and babies in the long run. She told me that a few mothers were abusive, but most were just a bit overprotective. This was scant preparation for the blast of my own emotions over the next two years or so.

What parents do offer other parents, through literature and friendship and organized peer support, is respect—with empathy—and without the burden of clinical assessment—a precious resource for families in crisis. Ideally, the survival skills that only parents know are added to the rich expertise of professionals, who cure and teach and understand in a different way.

It is no accident that handbooks like Helen Harrison's "The Premature Baby Book"—written by parents—contain the kind of information that empowers: personal stories that illustrate and sanction the range of normal emotional reactions, definitions, rights, practical information, skills, facts about survival rates and what is known about prognosis. They don't offer protection from needless anxiety: parents know that parents of disabled and at risk babies are already anxious. What parents do offer other parents, through literature and friendship and organized peer support, is respect—with empathy—and without the burden of clinical assessment—a precious resource for families in crisis. Ideally, the survival skills that only parents know are added to the rich expertise of professionals, who cure and teach and understand in a different way.

I have spent a lot of time since Nick was born examining how I felt and functioned as a mother when he was ill, turning over in my mind relationships with professionals and my family and other parents. The most destructive factor during that period was my own difficulty in accepting my emotional reactions. Viewed more objectively, the mechanisms that defend us from despair are logical. Guilt implies a comforting measure of control over a situation with no rational explanation. Anger defends us against blame. Emotional detachment numbs the fear of loss. Denial gives us time to learn new ways of coping, and the energy and humor to fight the facts in ways that sometimes generate new services and better

futures for our children.

Those mechanisms were logical and necessary, but at the same time they insulated me from the people that I loved as well as from the painful facts of Nicky's illness. I wondered what was wrong with me, and I was too vulnerable to the judgments of the professionals who cared for Nick to ask for their help directly. I pretended to be more competent than I felt, and missed opportunities for help. I was defensive and demanding. I found fault with them for keeping a professional distance, thinking that if they would just become personally involved with us, they could provide the emotional support we needed.

I was at an inservice once that dealt with infant death. I was sitting with my arms crossed, feeling irritated because a young unmarried social worker, rather than a parent, was speaking about what families need, when a nurse stood up and described her difficulty in coping with the death of a baby to whom she had become attached. She talked about how terrible it had been to go into the nursery the next day and see another baby in the crib. She made me see the magnitude of my demand for personal involvement. Like families, professionals must build the defenses that allow them to function in the face of human tragedy.

But families do need nurturing, and I am still angry five and a half years later at the professionals who were too insensitive or unskilled or human to give me what I needed. I am still mad at the doctor who said, when Nick was three days old, that I was in an awfully good mood for someone with such a sick baby. I am mad at the nurse who last week told another mother, who called at 11:30 at night to check on her 2 lb. 3 oz. son before she went to sleep, that she should call back in an hour, after rounds. The reason that these incidents are worth recalling here is not to prove that, like other people, professionals make mistakes, but because cumulatively their impact on families is profound, and if we care for babies we *must* meet the needs of families.

When my daughter Bess was born, one of the unexpected benefits was membership in a community of parents who brought me chicken soup and nurtured

me through the uncertainties of first time motherhood. Like me they were fallible, and like me they were available for listening to theories and insights and frustrations. We served each other as a base line for determining what was normal in ourselves and our children.

Once I made contact with other parents after Nick was born I found the same remarkable resource. Other parents again provided me with a context—often just by listening without trying to reassure me; sometimes by reinforcing half-formulated plans of action; occasionally by confiding fears that mirrored my own. My own healing during Nicky's illness began with those parents. Finding them was surprisingly difficult. Through policies of confidentiality and professional territoriality, the system impeded our access to each other instead of encouraging this crucial human contact.

During much of Nick's early life the successes in coping with his problems belonged to professionals. Only the failures were mine.

Nick had chronic lung disease and was on oxygen until he was nearly a year old. He was rehospitalized several times after his first two and a half month stay in intensive care. One September day when he was just over a year old, he laboriously rolled himself to my dresser and reached up to play with the shiny brass drawer pull. I realized with a start that it was the first thing he had ever done that had reminded me of his sister Bess. Our questions about his development didn't begin to have answers until he was nearly two.

During much of Nick's early life the successes in coping with his problems belonged to professionals. Only the failures were mine. I hadn't had a healthy baby, couldn't seem to get him healthy, couldn't comfort him and, most painful, I didn't feel connected to him. I believed that I wasn't capable of doing him any good. I would like to read a poem that I wrote about surviving that period in our lives.

Bonding

Three years old on Tuesday,
think of it.
Two years ago I didn't know that I could love you,
precious boy.
I look at pictures of that year,
and see your smiles,
and wonder how I could have missed them then.

But we were both so needy that first year:
you for breath and growth,
I for the healthy son who would reflect my strength,
not demonstrate my failure.
I gave you all I had that year,
but numb with fear of doing you more harm,
I had so little.

Yesterday, looking at the pictures of your big sister
(I think you'd never thought before that she was once so small),
serious and funny, you turned to me and said, "She was little
and when she was born she was very, very born."

No degree of being born,
and yet for us there was a kind of prelude.
Three years since you were born,
Two since we began
the important part.

Like most other families, we were left alone, to sort out these complicated emotional issues. Two things would have helped: emotional support and information.

Sometime after Nicholas had started nursery school I saw a grainy, black and white videotape that demonstrated what Dr. Brazelton calls the "irresistable responsiveness" of a premature baby. I almost cried while I watched as a 3 lb. preemie slowly followed a ball with his eyes, looked for the sound of his mother's voice, and with heroic effort, finally turned his head and even reached for her. A nurse practitioner had taught that mother to read the subtle clues that could have drawn me to my son so much earlier. It was a piece of information, a teachable skill, that might have changed the course of our lives.

Emotional support, too, was hard to come by. The cornerstone of this experience is loneliness. Our family was isolated by the physical realities of hospitalization and therapy sessions, isolated socially by an experience that few other families share, isolated from each other by the crisis itself, with each family member needing to curl up somewhere for comforting.

The most realistic way to decrease families' isolation is by providing them with access to their peers: the other families for whom this contact is part of their own healing. Peer support is just a fancy name for what happens in the office, and the grocery check out

line, and the halls of nursery school: mothers and fathers and business executives testing the accuracy of their own perceptions, and moving from the isolation of their own feelings into their context as members of the human race.

Families who have children with disabilities are first of all families.

But it can be a complicated task for families of disabled and at risk babies to find their peers—particularly during the first few months or years when the future is a list of unimaginable possibilities rather than a clear diagnosis. Nick was nine months old before I met a mother whose baby had similar problems. I will never forget the incredibly intense feeling of recognition and kinship that I experienced during that hour-long talk in a hospital cafeteria. And later, as our parent group flourished, I saw so many other mothers and fathers experiencing the remarkable sense of connection that had kept a group of strangers talking in a hospital parking lot until midnight after our first meeting.

As parents and professionals we can best accomplish the difficult job of meeting families' needs by utilizing each other as practical human resources. Parents developing literature or programs containing medical or educational information must turn to professionals for guidance. Professionals developing services for families must draw on the special expertise of families. A few years ago, I saw an intensive care nursery parents booklet developed by nursing staff. The project had been undertaken generously as a service to parents, and the booklet contained good information, but it began with a list of prohibitions and its terminology "allowed" visiting, rather than encouraging it. Exactly contrary to its purpose, it subtly reinforced the powerlessness of parents.

Helen Featherstone said that when parents tell about discovering their children's handicaps, their descriptions invoke images of cataclysm. As we care for these families we must respect the magnitude of their task. As they rebuild their lives, we must aid them in ways that increase their strength and build their self-esteem. It behooves all of us to set out from here determined to develop a forum where parents and professionals can share the valuable and hard-won knowledge that each of us possesses.

Family Relationships

LISBETH J. VINCENT, Ph.D.

I'm pleased to have the opportunity to share with you our findings from research and demonstration efforts in the last ten years as we have worked with families who have members who are handicapped. I think that we need to be aware that this includes a lot of Americans. Bob Perske recently quoted some figures that would say 60 million Americans have someone in their family who has a disability. I hope this evening that I can not only represent research, but that I can also represent those families, their lives, and what they have taught us as well as what we have learned from them. I think first of all we need to remember that families who have children with disabilities are first of all families. The major finding, I think, of the past ten years is that the American family has changed. The Ozzie and Harriet, Leave it to Beaver, Mommy stays home, Daddy goes to work, is no longer a reality in America. It is also not a reality that is going to return. I think that is very difficult for most of us, who, if you're like many of my colleagues, were raised in two parent homes where mommies did stay home until you graduated from school. I think it is very difficult because the change in the American family has caused and causes many of us to reexamine our values, to relook at what we believe about family.

How much has the family changed? Last year 15% of the births in America were to single mothers. We have predictions that by the year 2000, that will be as many as 25% of the births. Last year we knew that 40% of the teenage women in America conceived children—teenagers not young adults. Many, many of those women chose to deliver those children, and over 90% chose to keep those children, raise them as teenagers, and in most cases reduce their own education and their own achievement. We now know that there is great probability that 67% of the children in

America will spend part of their time being raised in a single parent home. The majority of children now spend time with single parents, not the minority. We know that as a culture we are facing an increase in drug and alcohol abuse; we've seen an increase in child abuse; we've seen an increased awareness of childhood sexual abuse. Unemployment, although it is better now, it still a major factor in many sections of this country, and effects families and children every day. Currently, over 50% of the mothers with preschool age children are out in the work force, and we predict that by the year 2000 that will be up to 75 or 80% of the mothers in America. We have 3 and 4 year old children in this country who are responsible for themselves for anywhere from 5 to 8 hours a day. They are latch key kids. They fix their own meals. They make it out on the street.

It sounds like a lot of bad news, doesn't it? I think that I would like to give you a contrast, and that is that yes, the American family has changed. Right now the American family can be characterized as a group of people in transition who face a great deal of stress. But, at the same time, we have to note that the American family is being successful. More children are finishing school. More children are achieving better grades. We are lowering some levels of crime. We're being successful in integrating individuals with handicaps into society.

So the family is changing from what you and I grew up with. It's changing from our values, but it's not being less successful. It's solving its problems in its own way. It's solving its problems in a different way. And in a sense, if we want to characterize the typical American family today, we'd have to say there's not a typical family. Variety and difference, single parents and joint custody, cooperatives, dual parents all characterize a part of our society. Now I think what's very important about this when we look at families with children with handicaps is to realize that they face the same stress. They are undergoing the same change that families in general have undergone. Recently in Madison—we serve 300 young handicapped children and their families between birth and six in the school district and we just finished a survey

of all those families—we found out that 52% of them are single parent families, 47% have experienced significant unemployment this year, 17% have documented cases of child abuse and neglect. These are families. That's just like America, and they're not different in terms of those characteristics.

The family is a group of people who live together and solve their problems day to day; they use lots of different solutions; most of the time those solutions are not professional.

I think the biggest problem we face, as early interventionists, is that most of the models that we have developed to work with these families were developed in the late '60s and early '70s. They were based on early intervention projects where moms brought children to a center and stayed around, or we went out and did home visits during the day and moms were here to greet us or we did parent meetings in the evening and all of the parents dutifully came in and attended our parent meetings. And those are our models. That's what we are using and we face a big problem. I think the greatest lesson of the last five years has been a need to change as professionals. We need to look at new approaches to families. We need to recognize the resilience of the American family even though it's different than ours, and we need to realize that we are not going to be able to have one approach or one program or one set of parent meetings or one manual that fits every parent. We're not going to be able to demand that they meet those kinds of expectations. For if we do that, we will lose their children. We will be unable to provide the quality of intervention services that my other colleagues have spoken to this evening.

So, the question is what do we need to do? What are the kinds of changes? What are the approaches that might be successful in dealing with this new American family? I think that we are very fortunate in the last five years to have some researchers around this country, e.g., Michael Berger and Martha Foster down in Atlanta, Georgia, and Ann Turnbull and her colleagues out in Kansas, who have forced us to look at networks. They have forced us to recognize that the family is a group of people who live together and solve their problems day to day; that they use lots of different solutions; that most of the time those solutions are not professional. The solutions involve "their" people. Who are "their" people? Last summer

in Madison, we did a study looking at parents of preschool age normal children and handicapped children. We asked them who do you talk to about your kids? Who do you go to when you have problems? We found no differences, by the way, between families with handicapped children and families with typical children. What was the first thing they did when they had problems? They relied on themselves. They used their own motivation. They use their own persistence. What was the second thing they did? They went to spouse or lover or coparent. What did they do next? They went to extended family. Where did they go next? They went to friends, next coworkers, last professionals. And, in fact, 75% of the choices of the people, in terms of how to solve their problems, rested in the informal network. I think that most of you, if you were to do an analysis of your own life, will realize that that is probably the system you use as well. You don't turn to professionals first. You turn to your own resources, you use your own resources. The implications of this for early intervention programs is that we need to learn to tune in to the capabilities of the family. We need to learn to do better jobs of assessing their networks. We need to develop some programs as Bob Wahler is doing down in Tennessee to teach families to expand their resource network. Some preliminary results coming out indicate that child abuse is more likely to occur in families with limited resource networks, and that the isolated family that has few people to rely on is the family who is at risk. That family may be well educated, that family may have a great deal of money, but the lack of people resources may eventually cause stress. So, we need to look to networks. We need to look to ways to teach families to build better networks, to use the networks they have, rather than coming to us, rather than relying on us. We need to look to bridge families into existing community programs, rather than always creating separate programs for families who have handicapped children. We need to remember that the family is capable of generating solutions to its own problems, and that our roles should be to assist them as they generate those solutions.

At the same time, we need to remember that young children with handicaps need quality intervention services. I'm not advocating that we remove educators, therapists, nurses, and child development specialists from working with young children with disabilities. Young children need these specialists, but families need a slightly different approach.

I think that if this approach is going to be successful, we have some barriers that stand in the way that need to be removed. The major barriers that I identify are attitudinal barriers. They are a set of beliefs that we have evolved as professionals, and I have certainly had these beliefs myself. I'm not sure where these beliefs came from, but they are certainly beliefs that need to be changed.

The first negative belief that I would like to talk about tonight is that parents and family members do not know what their children can do. There is a very strong overriding belief in any educational community that when parents say a child can do a skill, if I the professionals have not seen it happen, of course, the child cannot do it. There's almost this belief that parents lie to us. I have never figured out why they would lie to us; I have never figured out what they have to gain by lying to us; but we hold parent opinion as suspect. We hold parent opinion as not valid.

I was talking to Diane Bricker today and in her project where they're having mothers rate the development of their premature infants, there's 80% agreement between parents and professionals as to what's happening to the kids. A recent survey on normal preschool age kids showed a 90% overlap between teacher and parent rating of child behavior. Some of those studies have also gone in, by the way, and looked at when we disagree, who's more likely to be right? 75% of the time it's not the professional who is likely to be right. It's the parent. A recent study demonstrated that the most accurate person in terms of assessing the child's development was the mother. The second most accurate person was the father. The third most accurate person was the teacher. The least accurate person was the school psychologist, who we allow to decide placement of handicapped children in different programs. Parents do know

what their kids can do. They're reliable observers. They do differ from us and one thing that the parents do that the professionals don't, and it's personally one of the things that I find most delightful about parents, is that they give children credit for emerging skills. They see them starting to do things and maintain the hope that that will evolve into a full blown skill in the future. I certainly hope as professionals that we reinforce parents in that kind of optimism and that kind of quest.

Parents give children credit for emerging skills. They see them starting to do things and maintain the hope that that will evolve into a full blown skill in the future. I certainly hope as professionals that we reinforce parents in that kind of optimism and that kind of quest.

The second negative attitude, and it grows out of the first, is that parents do not know what appropriate goals are for their children. They do not know what their kids need. They don't know what they should be working on. We, as professionals, need to decide the goals. The parents really can't do this. Fortunately, we have professionals such as Irene Carney and Marti Snell down in Virginia who are working with families on doing lifetime planning for their individual members with handicaps. They are helping families project the kind of community involvement they would like and are showing that parents can look very easily to the future.

In my own experience, I did a workshop in Canada last year for a group of 75 parents who had young adults with disabilities, 16 to 20 years of age. I asked them as part of the workshop to write down on paper for me what were the five goals that they would like their handicapped adolescent to achieve by 21 years of age. As professionals, we have a fairly strong belief that parents can't agree, that they usually don't agree on what they want, yet out of this group of 75 parents came three common goals that every single parent listed. The first was I want my child to be happy and have friends. Now this is a goal that many of us in the field of early intervention find a great deal of difficulty dealing with. As soon as a parent says this to us we say, "Well, yes, but why don't we look at today and let's work on supportive sitting, or rolling over, or reaching out" or a developmental milestone that will be observable to us. Just last week in a multidisciplinary team meeting I was in, a dad of a young 14 month old, very severely handicapped son, said to me, "There are lots of things

I'm worried about, but if there's one thing I wish you could promise me it would be that someone would care about my son who doesn't have to. Then I would be ok for the future. If you could promise that someone would care who isn't paid to, who isn't a family member, than I'd be ok for the future." I think that we are at a point that we should be able to promise that as a society, that we should allow parents to express those goals and those objectives to us.

The second goal that the parents in Canada mentioned was I'd like my child to be able to give back, to contribute to society. Some expressed this in terms of working for pay, others in terms of volunteer work. The third goal was that the child be able to live away from home in a community setting, e.g., a group home or semi-independent apartment, not an institution. These three goals, happiness, contributing to society and community living are surely goals we can share and support as professionals. They reflect the accuracy and appropriateness of goals parents choose.

The third negative assumption that we make about parents is that they do not know how to teach their kids. Now we don't do this in early childhood because we all know that the parents are the first teacher, best teacher, the most primary teacher. We can go through the litany. The reality though is that a lot of what we do say to parents is that you do not know how to teach. We continuously tell them how to do it our way. Our way being what we did in a classroom or what we did in a clinic or what we did in a lab. We give them that advice often unasked for, and usually without finding out whether they've had any ideas themselves on how to effectively teach. We know parents can teach. Starting way back in 1969, 1970, the Portage Project demonstrated that parents teach very effectively. Marcy Hanson demonstrated that with the young Downs syndrome infant program out in rural Oregon. John Filler and his colleagues have redemonstrated it by having parents work on skills that are not being worked on in the classroom. But we need to do more to support and confirm the parents' role as teacher.

The last negative assumption, and this is one that is very difficult, is that parents need us. Parents need

professionals' help. That's a real difficult assumption. Ann Turnbull said to me, "You know, Lisbeth, if you're going to say that, you'll also have to say to people, remember, there is one thing the parents need professionals to do and that is they need us to do our job." They need us to do it right, they need us to do it on the cutting edge, they need us to do it consistently, and they need us to do it without having a fight, without having to go into the courts, without having to monitor us. They may need us to help them learn about their resources. They may need us to help them learn to meet other families who face the same problems they do, but they don't need us to solve their problems.

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So, I think that if we're going to be successful with families, and if we are going to make the kind of difthat ference families are interested in, that is, to impact on the critical life space of an individual who has a disability, we're going to need to reorient as professionals. We're going to need to look to parents as leaders, parents as the experts, parents as the bosses. We're going to need to ask them to join us cooperatively as equals in this partnership so that we create a reality out there that matches what all of us want to see.

In order to share with you what that reality looks like, I would like to tell you of a dream that was evolved by Nancy Kaye, an individual who was handicapped herself, and a series of parents and myself over the years. The dream was that we as families, we as professionals, would know that we had made it in the field of special education if the following thing happened:

A young couple who had several elementary school aged kids moved to a community, approached a real estate agent to buy a house and indicated they wanted to be in a neighborhood school district. The real estate agent showed them several homes and they said, "ok, this is fine but do any of these elementary schools serve children with disabilities"? "Oh, well, yes." "Well, that's good. Our children don't have any disabilities, but we really think that theirs would be a more valuable education if they had the opportunity to share it with people who are different. Do you know, if as part of that program, the children with

disabilities are integrated with normal kids"? "Well, yes, they are." "Well, ok, now my husband and I also believe that our lives are enriched if we're part of a community that includes individuals with differences? Do you know if this neighborhood includes individuals with differences. Do you know if this neighborhood that you have selected has a group home for adults that have disabilities? Are there semi- independent apartments here? Will we be able to have in our friendship network people who show unique differences"? "Yes." "Oh, there are. Well, that's good. Well, we noticed that there are lots of little stores around here. Do you know if these little stores employ people who display disabilities? Will we be able to see as part of our work life folks who have had to overcome obstacles which we have not had to overcome"?

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I was telling this story to a group of parents in Indiana, and at this story to a group of parents in Indiana, and at this point a young father in the audience raised his hand and said, "Dr. Vincent, I hate to tell you this, but you've really missed the point." And I said, "Oh, what's that"? And he said "well, if we'd really made it in America, if we had really teamed up, if we really knew what we were doing, if we had really gotten there, the young couple wouldn't even have had to ask those questions of the realty agent." I concluded that the Dad was right. If we really had made it, we would be able to achieve as a society what families achieved for years. They have successfully mainstreamed individuals with disabilities. They haven't worked on tolerating difference like we talked about in the early '70s. They haven't worked on accepting difference like we talked about in the early '80s. They have worked on a step beyond that we need to join them in as professionals, and that is that they have worked on cherishing the members of their families with disabilities for who they are, for what they teach them, for what they give them, for what they are able to learn. So I hope that we will be able to join with families, and with them work toward a better effort so that we won't have to ask the questions of the realty agent. Our society truly is a better place if individuals with handicaps are fully integrated into our day to day lives.

Kathryn Elaine Barnard, Ph.D.: Professor of Nursing, University of Washington, Seattle; Principal Investigator for Nursing Research Fellowships in the area of Parent Child Interaction, National Research Service Award from the Division of Nursing, PHS/HRA/DHEW; Nursing Child Assessment Training Project under a grant from Harris Foundation & Maternal Child Health Services; PHS/DHHS. She is involved in a study of the long term effects of rocking/heartbeat stimuli on premature babies, sponsored by the Robert Wood Johnson Foundation, and is investigating most effective ways in which nursing care can be provided to families of high risk newborns to promote mutual adaptation. She is on the National Foundation March of Dimes Advisory Committee for Perinatal Nurse Education, and consultant to University of Michigan and Utah and Wisconsin projects.

Julianne E. Beckett, M.A.: She is a full time social studies teacher in a junior high school in Cedar Rapids, Iowa, and Chapter Director for Sick Kids (need) Involved People of Iowa, a multidisciplinary non-profit organization helping parents and professionals realize the advantages and the needs in home health care. She is working to help develop a regionalized system of home health care for the state of Iowa and to plan the Surgeon General's Regional Workshop to be held in Dallas, Texas. She is the mother of Katie Beckett, an 8 year old ventilation assisted child recovering from the afteraffects of viral encephalitis.

Page Talbott Gould, Ph.D: Has a Ph.D in American Civilization and is currently a museum consultant in the field of American Art. She is the mother of 3 premature babies, the smallest of whom weighed 1 lb. 10 oz. at birth. The youngest, a 3 month old girl who was ill with a respiratory illness, is doing fine now. Ms. Gould is the founder and Co-President of Intensive Caring Unlimited, a Philadelphia based organization for parents of premature and high risk infants and women experiencing high risk pregnancy. She is also founder and former board member of Parents of Premature and High Risk Infants International, Inc.

Fern Kupfer: Parent, author of *Before and After Zachariah*. Zachariah, now eight years old, is a severely handicapped child living out of the home for the past five years. She wrote the book *Before and After Zachariah* to help people understand what living day-to-day with a severely handicapped child is like and to offer institutionalization ("placement") as a *positive* alternative. She has written for *Newsweek*, *Redbook* and *Ladies Home Journal* and sees herself as a parent advocate. Currently, she is living in Ames, Iowa with her husband

and their daughter, age 12. She writes and teaches writing at a community college.

Lenette S. Moses: Co-president of the Philadelphia area parent support group Intensive Caring Unlimited, one of the largest such groups in the country. Her son Tim was born at 28 weeks gestation due to DES exposure. He suffered intercranial hemorrhages, respiratory distress syndrome, bronchial pulmonary displasia, meningitis, and other medical problems during his 10 weeks hospitalization. He is now 4½ and has some minor gross motor, fine motor and cognitive delays. Lenette also has an 18 month old son, Ted, born after a high risk pregnancy. She is a free lance writer and designer by profession.

Ann Oster: Following the premature birth of her second child in 1979, Mrs. Oster organized Parents of Special-Care Infants, Inc., a volunteer peer counselling network which served families in eight Baltimore area hospital special care nurseries. She is a founding director of Parents of Premature and High-Risk Infants International, Inc., and a member of the Maryland delegation to Project Zero to Three. Currently the Special Projects coordinator at the Maryland Committee for Children, Inc., Mrs. Oster has also worked as a free lance artist and a children's librarian.

Lisbeth J. Vincent, Ph.D.: Associate Professor, Department of Studies in Behavioral Disabilities, University of Wisconsin. Dr. Vincent's major area of emphasis is early childhood/special education. She serves as a resource to public school based programs for handicapped infants and their families. She is involved in designing models and materials for active decision making by parents.

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